PART II:

INNOVATIVE END-OF-LIFE CARE COMMUNITY SERVICES

CHAPTER 5

A PATHWAY TOWARDS EVIDENCE-BASED COMMUNITY-BASED END-OF-LIFE CARE IN HONG KONG: BUILDING A COMMON EVALUATION FRAMEWORK

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End-of-life care (EoLC) in Hong Kong is mainly provided by specialised units in hospitals. The foreseeable growing demand for EoLC presents a pressing need to develop strategies in the community to share the care. Under this context, the Jockey Club End-of-Life Community Care (JCECC) Project was launched in 2016 to bring together service providers and academics to build evidence- and community-based EoLC models. Four discrete community-based EoLC models have been developed and piloted. To generate knowledge and insights regarding the outcomes and implementation of these four models, the Faculty of Social Sciences, University of Hong Kong (HKU), developed a common evaluation framework. This framework is the first of its kind in Hong Kong. There has been a proliferation of evaluation studies in EoLC in the international literature, although evaluation studies on EoLC in Hong Kong have been developed more slowly (Wang & Chan, 2015). This chapter presents the key issues, and a summary of major work pertaining to EoLC evaluation conducted worldwide. It introduces the common evaluation framework developed for the four JCECC Project models. Descriptive findings from the evaluation are then presented. Experiences of implementing the new evaluation framework, learning and implications for future advancements are discussed.

BACKGROUND

KEY ISSUES IN EVALUATION IN COMMUNITY-BASED EoLC

Conceptualising outcomes of community-based EoLC. Formal programme evaluation is essential to generate the evidence needed for continuous quality improvement. Different types of evaluation have been reported for EoLC, focusing on input/structure, process, output and/or outcomes. Among these, outcome evaluation is gaining prominence in EoLC to inform care outcomes that directly affect patients and their families. Outcome evaluation is key to quality improvement, as well as benchmarking and comparisons across care models (Bausewein et al., 2016). Defining outcomes of EoLC is not without its challenges due to the heterogeneous definitions of EoLC. The World Health Organisation (WHO) defined palliative care (PC) in 2002 as an approach that improves the quality of life (QoL) of patients facing life-threatening illness and their families. PC can assist in the relief of pain, as well as other physical, psychosocial and spiritual problems (Worldwide Palliative Care Alliance, 2014). Improving QoL has become the primary goal of PC, and the core indicator in outcomes evaluation of EoLC. In 2013, the National Consensus Project in the US established clinical practice guidelines, which defined eight domains of preferred care encompassing the WHO definition of PC (National Consensus Project, 2013). These domains are:

1. Structure and professes of care
2. Physical aspects of care
3. Psychological and psychiatric aspects of care
4. Social aspects of care
5. Spiritual, religious and existential aspects of care
6. Cultural aspects of care
7. Care of the patient nearing the end of life
8. Ethical and legal aspects of care

In a recent systematic review on assessment tools, a ninth domain was identified as “multidimensional”, which promotes the concept of multidimensional QoL (Aslakson et al., 2017).

Studies examining the domains of preferred care have provided consistent evidence to show that EoLC is more effective than conventional care for patients at EoL (Catania, et al., 2015; Kavalieratos et al., 2016; Potts, Cartmell, Nemeth, Bhattacharjee & Qanungo, 2018). The most recent systematic reviews suggested that palliative EoLC benefitted patients with improved QoL, physical symptom relief, Advance Care Planning (ACP), patients’ (and families’) satisfaction with care and reduced healthcare service utilisation (El-Jawahri, Greer & Temel, 2011; Kavalieratos et al., 2016; Zimmermann, Riechelmann, Krzyzanowska, Rodin & Tannock, 2008). These reviews provide clearer conceptual frameworks regarding outcomes of EoLC for evaluation studies.

Selecting outcome measurements. A core challenge in selecting outcome measurements in EoLC is the large number and variability of existing instruments, which render meaningful comparison across research and meta-analysis difficult (Aslakson et al., 2017). In a systematic review conducted in 2007, 80 of the 97 studies included outcome instruments in PC that had been reported only once (Mularski et al., 2007). Moreover, many outcome instruments were criticised for questionable psychometric properties and irrelevant content, length and impracticality in clinical settings (Mularski et al., 2007; Stiel et al., 2012). Leading PC research organisations have advocated the use of standardised assessment tools, for instance:

- The US National PC Research Centre has recommended a core list of outcome measures (National Palliative Care Research Centre, 2013); and
- The European Association for Palliative Care (EAPC) Task Force was formed to develop nationally comparable assessment tools across Europe and to promote integration of outcome assessments in routine clinical care.

Subsequently, the EAPC Task Force published a White Paper in 2016 to provide expert recommendations regarding the selection, use and implementation of outcome measures in PC (Bausewein et al., 2016). Twelve recommendations were proposed. Four of these, summarised in **Table 5.1**, outline useful key decision-making parameters for selecting good outcome measures in terms of instrument design, psychometric properties, assessed domains and targeted subject(s). The use of patient-reported outcome measures (PROMs) was highlighted by the Task Force as a way of capturing patients' experiences as the ultimate outcome information. Hearing patient experiences can serve as a way for patients to provide feedback on unmet needs. Moreover, the EAPC Task Force recommended embedding outcome measures into routine clinical practice, particularly advocating for the use of outcome measures that have been translated into other languages using validated processes to support comparisons at national and international levels (Bausewein et al., 2016). **Table 5.2** summarises the properties of commonly used PROMs and outcome measures for caregivers that could contribute to clinical and research activities in EoLC.

Table 5.1 ***Key Decision Parameters on Selecting Outcome Measures Proposed in the White Paper of the EAPC Task Force (Bausewein et al., 2016)***

	KEY DECISION PARAMETERS ON "GOOD" OUTCOME MEASURES
Measurement design	» Patient-reported outcome measures (PROMs) » Validated in PC » Brief and straightforward items » With complementary proxy versions to allow proxy reports when the patient is unable to self-report
Outcome domain	» Multidimensional measurement to enable capture of the holistic nature of PC
Subject to be assessed	» Using outcome measures to assess unpaid caregivers alongside patients' needs
Psychometric properties	» Outcome measures with sound psychometric properties (e.g. reliability, validity, responsiveness)

Two projects have been undertaken in an attempt to standardise outcome measure used nationally: Palliative Care Outcomes Collaboration (PCOC) in Australia (Palliative Care Outcomes Collaboration, 2018) and Outcome Assessment and Complexity Collaborative (OACC) in the UK (Witt et al., 2015). These projects share a similar goal of routinely incorporating agreed, standardised outcome measures into PC services in a range of care settings. The aim of this is to achieve a national clinical outcomes set that supports evaluation, quality improvement, comparisons across services and benchmarking. Both PCOC and OACC suites support holistic assessments for patients and caregivers, covering domains of illness, physical needs, psycho-spiritual needs and family care. The project teams are closely collaborating to align the tools in the two suites. Currow et al. (2015) demonstrated how the outcomes data collected with the PCOC suite has underpinned performance benchmarking, monitoring and improvement on a national level.

Table 5.2 *Properties of Commonly Accepted Outcome Measurements with Patients and Caregivers in EoLC Studies*

	EXAMPLES OF RECOMMENDED MULTIDIMENSIONAL PROMS IN LITERATURE			
	Edmonton Symptom Assessment Scale (ESAS) (Bruera, Kuehn, Miller, Selmser & Macmillan, 1991)	**Palliative Care Outcome Scale (POS) (Hearn & Higginson, 1999)**	**Memorial Symptom Assessment Scale (MSAS) (Lobchuk, 2003; Portenoy et al., 1994; Sherman et al., 2007)**	**McGill Quality of Life Questionnaire (MQOL) (Cohen, Mount, Strobel & Bui, 1995)**
Population of validation study	Patients receiving palliative care	Patients with advanced cancer	Patients with cancer	Patients with advanced illness
Time for completion (minutes)	5	4–7	20–60	10–30
Number of items	10	10	32	16
Assessed domains and items	Physical symptoms, psychological symptoms, general well-being and other concerns	Physical, psychological and spiritual needs, practical concern, family anxiety, sharing feelings with family, information needs and self-reported concerns	Physical symptoms, psychological symptoms and self-reported concerns	Physical and psychological symptoms, existential concerns, support needed, sexual function and perceived QoL
Internal consistency reliability measured	Y	Y	Y	Y
Convergent validity measured	Y	Y	Y	Y
Criterion/ discriminant validity measured	N/A	Y	N/A	N/A
Responsiveness measured	N/A	Y	N/A	Y
Availability of proxy version	N	Y	Y	N
Validated Chinese version	Y (Dong et al., 2015)	N (validation on Chinese version IPOS is underway in Hong Kong)	Y (Lam et al., 2008)	Y (Lo et al., 2001)

EXAMPLES OF RECOMMENDED ASSESSMENT TOOLS ON CAREGIVERS IN LITERATURE

Modified Caregiver Strain Index (Thornton & Travis, 2003)	**Short-form Zarit Burden Inventory (Higginson, Gao, Jackson, Murray & Harding, 2010)**	**Inventory of complicated grief (Prigerson et al., 1995)**
Caregivers for patients with advanced cancer	Caregivers for persons with dementia and cancer patients	Bereaved adults
N/A	N/A	N/A
13	12	19
Multidimensional caregiver strain, both subjective and objective aspects	Items on role strain, self-criticism, and negative emotions	Symptoms of complicated grief
Y	Y	Y
Y	Y	N/A
N/A	N/A	N/A
N/A	N/A	N/A
/	/	/
Y (Chan, Chan & Suen, 2013)	Y (Tang et al., 2015)	Y (Li & Prigerson, 2016)

Strategies for improving evidence base in EoLC. PC and EoLC have long been criticised for having a weak evidence base. In a review of literature published in 2004 and 2009 (Hui et al., 2011), only 5.6% palliative oncology studies conducted in the first six months of these two years applied randomised controlled trial (RCT) designs. A more recent review identified that of all PC studies published between 1946 and 2015 only 11.4% were controlled clinical trials (CCT) (Bouça-Machado et al., 2017). Moreover, many clinical trials have been criticised for methodological flaws, such as high-risk of bias and low power (Visser, Hadley & Wee, 2015). In reality, however, it is challenging to conduct high-quality PC research, particularly with a follow-up element in the design. Many clinical trials in PC have failed to recruit the required number of participants (Hanson et al., 2014), and a high median attrition rate (44%) has been reported (Hui, Glitza, Chisholm, Yennu & Bruera, 2013). Patient factors such as symptom burden and clinical deterioration are reported to be the main barriers to adequate recruitment and retention, followed by caregivers' gate keeping (limiting access to patients) and ethical concerns (Dunleavy, Walshe, Oriani & Preston, 2018). Some studies have managed to achieve better recruitment results with the use of standard recruitment protocols and specialised recruitment staff (Dunleavy et al., 2018; LeBlanc, Lodato, Currow & Abernethy, 2013). Other studies have attempted to improve recruitment by modifying study designs (such as the use of a randomised fast-track trial with patients who have longer term prognoses; Higginson & Booth, 2011). Globally, there is an increasing trend of conducting large-scale, multi-site, high-quality collaborative research in PC by concerted cooperation between interdisciplinary research groups. The Palliative Care Research Cooperative Group in the US is one example (LeBlanc et al., 2010).

PC is a complex intervention, and mixed-methods research designs have been advocated to ensure comprehensive, in-depth, quality evaluations of processes and impact (Farquhar, Ewing & Booth, 2011). Mixed-methods designs provide many advantages to evaluators. They combine quantitative and qualitative research approaches, which not only facilitate holistic hypothesis generation, but also produce synergistic data that augments understanding of the mechanisms that produce study outcomes (Farquhar et al., 2011; Farquhar et al., 2013).

In summary, the development of international EoLC evaluation models has been characterised by increasing agreement regarding the need for evidence to support continuous quality improvement activities; use of standard outcome measures; routine incorporation of outcome measures into clinical practice; use of mixed-methods research to provide comprehensive evaluation data; and the importance of international research collaborations to enhance the global EoLC evidence base. It was therefore important when conceptualising the JCECC Project evaluation framework that it reflected these global advances.

THE HONG KONG SCENARIO

There are currently no systematic, agreed, routine outcome evaluation processes in place for EoLC. PC in Hong Kong is predominantly provided by hospitals under the auspices of the Hospital Authority (HA). The HA called for standardisation of data capture and alignment of outcome measurement tools in its sites to assess the performance and outcome of PC services (HA, 2017). This mirrors the mission statements of international groups such as PCOC and OACC, and it addresses a pressing need to develop an acceptable outcome assessment framework for PC and EoLC in Hong Kong. EoLC is provided in other settings (such as residential aged care settings); however, evaluation of such care in these settings is rare. Most studies into EoLC in Hong Kong are descriptive, and a systematic review of articles published in Hong Kong between 1991 and 2014 identified that clinical trials accounted for only 3.7% of all published local research (Wang & Chan, 2015). Pilot evaluation programmes have been implemented by major non-governmental organisations (NGOs) in Hong Kong; however, the evaluation frameworks and findings are not publicly available. Recently, an RCT of a nurse-led home-based PC programme for patients with end-stage heart failure reported significant improvements in favour of the intervention group (Ng & Wong, 2018; Wong et al., 2018). However, the study focused on only one disease group and the model was hospital-based. There is opportunity for improvements to be made in research on different community-based models of community-based EoLC, as well as for other disease groups.

THE JCECC PROJECT COMMUNITY-BASED EoLC MODELS

The four JCECC Project community-based EoLC models all involve complex interventions offered by multidisciplinary care teams. These models of care serve patients aged at least 60 years old who have been diagnosed with an incurable disease and who have a prognosis of six months or less. The models of care also serve family members.

1. The model of care provided by the Haven of Hope Christian Service is characterised by intensive home-based nursing care, Advance Care Planning and spiritual care.
2. St James' Settlement care model focuses on enhancing family communication and facilitating joyful and memorable moments through cheering-up activities.
3. The model of care provided by the Hong Kong Society for Rehabilitation takes a non-cancer patient capacity building approach, which promotes patients' competence in symptom management.
4. A community capacity building approach has been adopted in the care model delivered by S.K.H. Holy Carpenter Church District Elderly Community Centre. This model seeks to strengthen the support network of patients and families through building interfaces for patients and families with the medical team, community resources and volunteers.

Despite the differing care approaches, all four models are underpinned by strategic partnerships with hospitals, and they share the same six intervention foci in their holistic care:

1. Symptom management
2. Psychosocial care
3. Practical support
4. Family communication
5. EoL decision-making
6. Bereavement care

A pattern of interventions from the acute phase to the maintenance phase has been adopted in all models across disease trajectories. Approximately the first three months of care is called the acute phase. Intensive interventions are provided by the service team through visits and phone contacts. The care then moves to a maintenance phase, characterised by less staff involvement but regular assessment on changes in patient or family conditions which trigger interventions as changes occur. When the patient approaches death, staff involvement again increases to support the patient and family in the final days. Care is then provided during the bereavement period. More details on the interventions of each model are described in Chapters 6-9.

THE EVALUATION FRAMEWORK

The evaluation framework consists of four mixed-method sub-studies on patients and caregivers to assess the process, outcomes and impacts of the complex interventions (see **Figure 5.1**). Five specific objectives underpin these evaluations, which use different methodological approaches.

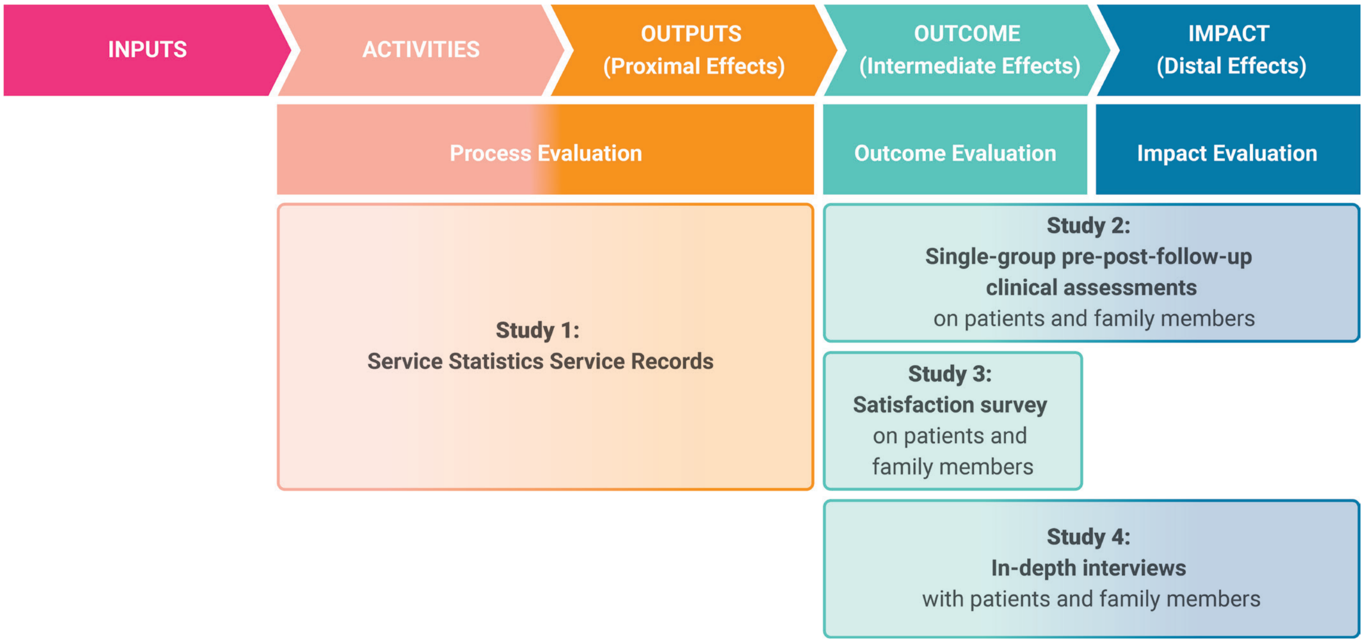

Figure 5.1 Evaluation Framework of the JCECC Community-Based End-of-Life Care Models

STUDY 1: SERVICE STATISTICS AND SERVICE RECORDS

Study 1 is a process evaluation of implementation of the models. This study enables optimisation of models when analysed with reference to programme outcomes. It collects quantitative data on service statistics, including the number of beneficiaries and service records, the number and length of service sessions, types of interventions and the healthcare professional(s) involved. A standardised service record form has been developed based on the six intervention foci common to the four care models. This study was implemented in the latter half of the second year of the project.

STUDY 2: SINGLE-GROUP PRE-POST FOLLOW-UP CLINICAL ASSESSMENTS

Study 2 evaluates objective outcomes and impacts of the care models on patients and caregivers. This study takes a quantitative, single-group pre-post follow-up design, with data collected by case workers through clinical assessments. During the development of the JCECC Project complex intervention models, the advice provided by the UK Medical Research Council guidelines (Medical Research Council, 2006) was adopted. This recommended that researchers start with small-scale, non-experimental studies to inform model refinement before embarking on a full-scale evaluation with more rigorous experimental designs. Since the four JCECC models are still evolving, a non-experimental observational design is currently considered appropriate for evaluation purposes.

The design of assessment time points should correspond to when the effect of the intervention is expected to occur (Evans et al., 2013). This was anticipated to be three months after completing the acute phase of care; however, given the high attrition rate of EoL patients, one additional time point has been introduced. Data are now collected from patients at service intake (T0), one month after service commencement (T1) and after three months (T2). Regarding caregivers, to reduce respondent burden, data are collected at two pre-death time points at service intake (T0) and three months after service commencement (T1). Since bereavement care is provided in all four models, a bereavement assessment has also been established two months after the patient's death (T2).

Outcome measures were selected according to key parameters recommended by the EAPC Task Force (Bausewein et al., 2016). For patients, the Integrated Palliative Care Outcome Scale (IPOS) was adopted to assess QoL. The IPOS is a recent development in the Palliative Care Outcome Scale (POS) suite of measures, proposed by scholars at the Cicely Saunders Institute of Palliative Care & Rehabilitation, King's College London. With approval from the POS development team, the IPOS was translated into Chinese by the HKU research team, and then validated by a standard forward–backward translation procedure supervised by the multidisciplinary professional group. The selection of IPOS is a proactive attempt to align the local evaluation with international developments in EoLC.

The IPOS (three-day recall) is a 19-item multidimensional QoL PROM with a complementary proxy version. It builds on the internationally accepted POS (Hearn & Higginson, 1999). Despite its relatively brief history, cultural validation studies of IPOS in different parts of the world are growing. Confirmatory factor analysis of the English version suggested a two-factor model was appropriate (Harding & Guo, 2017), including:

- A 7-item psychological and communication subscale that addresses psychological symptoms (2 items), spiritual needs, sharing of feelings with family members, perceived anxiety of family members, practical concerns and information needs; and
- A 10-item physical symptom subscale that addresses pain, shortness of breath, weakness, nausea, vomiting, poor appetite, constipation, sore or dry mouth, drowsiness and poor mobility.

All items are measured on a 5-point Likert scale ranging from 0 (best) to 4 (worst). The IPOS also includes an open-ended question on the patient's main problems in the preceding three days. Items can be analysed separately or summed as a total score ranging from 0 to 68, with higher scores representing more severe problems. In the current validation study, Cronbach's alpha statistics of the psychological and communication subscale, the physical symptom subscale and the overall scale were 0.75, 0.74 and 0.77, respectively. Empirical experience suggests that the average time for completion of IPOS is 10 minutes. The original English version of IPOS is free to use after registration on the POS website (https://pos-pal.org/).

For family members, outcomes of caregiver strain, perceived intimacy with patient and complicated grief are measured. The validated Chinese version of the 13-item modified caregiver strain index (C-M-CSI) (Chan et al., 2013; Thornton & Travis, 2003) was selected. The sum of the scale scores ranged from 0 to 26, with higher scores indicating higher levels of caregiver strain. The Cronbach's alpha statistic of the C-M-CSI in this study was 0.89. A single item was used to assess perceived intimacy with patients on a 0 (not intimate at all) to 4 (very intimate) scale. At T2, bereaved caregivers were assessed on their levels of grief using the 19-item Chinese version Inventory of Complicated Grief (ICG) (Tang & Chow, 2017). The items are rated on a 5-point Likert scale ranging from 0 (never) to 4 (always). A single factor was suggested, and respondents who scored over 25 on the scale were considered to have higher risk of complicated grief, which may require intervention (Prigerson et al., 1995). The ICG obtained a Cronbach's alpha coefficient of 0.91 in our study.

It is hypothesised that irrespective of which model of care is provided, it will promote psychosocial well-being of patients and caregivers, thereby reducing unnecessary medical service utilisation (of either group) of Accident & Emergency (A&E) presentations, admission to public hospital general wards or Intensive Care Units (ICU), or other medical services. For each time point, patients and family caregivers were asked about their use of medical services in the previous month. Per-month utilisation rates were compared between pre-intervention and post-intervention periods. Demographics, caregiving conditions and health status of caregivers were collected from patients and caregivers at T0. **Table 5.3** summarises the outcome indicators collected at each assessment time point.

Table 5.3 *Outcome Indicators by Assessment Time Point*

	MEASURE	DESCRIPTION OF ITEM(S)
Patients		
Psychological symptoms	IPOS	Two items on intensity of depression and anxiety
Physical symptoms	IPOS	Intensity of 10 common physical symptoms
Perceived family/ friends' anxiety	IPOS	One item on anxiety of family members perceived by patient
Communication of feelings with family/friends	IPOS	One item on difficulties communicating feelings with family members/friends
Practical concerns	IPOS	One item on severity of practical problems
Information needs	IPOS	One item on information needs
Medical services utilization	Utility items	Utilisation of 20 types of medical services
Demographics	–	Age, gender, disease group, financial allowance, living arrangement
Family member		
Caregiver strain	C-M-CSI	13 items on caregiving stressors
Intimacy with patient	Self-invented	One item on perceived intimacy with patient
Medical services utilisation	Utility items	A&E admission, hospital bed days in the last month
Complicated grief	ICG	19 items on symptoms of complicated grief
Caregiving situations	Self-invented	Hours per week providing care, days per week needed to accompany patient to medical clinics/hospitals, satisfaction with support from family members
Health status	Self-invented	Diagnosis of chronic diseases
Demographics	–	Age, gender, relationship with patient, income, living arrangement

Notes. IPOS=Integrated Palliative Care Outcome Scale; C-M-CSI=Chinese version modified caregiver strain index; ICG=Inventory of Complicated Grief.

	MONTHS IN SERVICE			
	Service Intake	1 Month	3 Months	2 Months Post-Patient's Death
	•	•	•	
	•	•	•	
	•	•	•	
	•	•	•	
	•	•	•	
	•	•	•	
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STUDY 3: SATISFACTION SURVEY

The objective of this study was to assess service satisfaction. A survey of patients and caregivers was taken at three months after service commencement, and a second survey was taken of caregivers, two months after the patient's death. Items were developed to assess satisfaction with each core service component and overall satisfaction. All items were scored on a 10-point Likert scale from 1 (very dissatisfied) to 10 (very satisfied). To maintain the objectivity of the findings, the survey was conducted independently of service providers by HKU researchers using telephone interviews. All patients and family members were invited, and the only non-completers were those unable to respond to the telephone survey. Each survey took 10 minutes on average.

STUDY 4: IN-DEPTH INTERVIEWS WITH PATIENTS AND FAMILY MEMBERS

Study 4 provides qualitative data on self-reported outcomes and service impacts, with the objective of obtaining individuals' perspectives of participating in the programme. Patients and family members were interviewed face-to-face using a semi-structured question guide. Two cases (patient and caregiver dyads) from each service model in each year were selected using a systematic sampling approach. Using the overall data on caseloads per year by each service model, these cases were identified at the 20th% and the 40th% of admissions to each programme in each year. They were invited to participate in an in-depth interview. Patients were interviewed after three months of receiving the service, and the caregiver interviewed two months after the patient had passed away. HKU researchers conducted and audio-taped the interviews. Interviews lasted for 30 and 60 minutes for patients and caregivers, respectively. Audiotapes were transcribed, and analysis was undertaken on the verbatim transcriptions. See **Table 5.4** for a summary of the four sub-studies.

Table 5.4 ***Summary of the Sub-Studies with Respective Objectives and Methodological Approaches***

SUB-STUDIES	EVALUATION OBJECTIVES	KEY QUESTIONS TO BE ANSWERED	METHODOLOGICAL APPROACH
Study 1: Service statistics and service records	Objective 1: To evaluate the implementation of the models and enable optimisation of models when analysed with reference to outcomes	» What types of interventions were provided? » Who provided the interventions? » What was the dosage of interventions?	Continuous collection of service statistics and service records recorded by case workers
Study 2: Clinical assessments with patients and family members	Objective 2: To assess the objective outcomes for patients and family members	» Did patient show improvements in quality of life and emotional states, and reduced medical service utilisation immediately after receiving services? » Did family caregivers show reduced caregiver strain and improved relationship with the patient after receiving services?	Single-group pre-post follow-up clinical assessment conducted by case workers Assess the changes in post and follow-up relative to baseline
	Objective 3: To assess the impacts on patients and family members	» Did the model reduce medical service utilisation of patients and family caregivers?	
Study 3: Satisfaction survey with patients and family members	Objective 4: To assess the subjective outcomes for patients and family members	» Were patients satisfied with the quality of care? » Were family caregivers satisfied with the quality of care?	Telephone survey with patients and caregivers conducted by HKU researchers Convenience sampling with invitation extended to all patients and caregivers
Study 4: In-depth interviews with patients and family members	Objective 5: To solicit in-depth and subjective perceptions of patients and caregivers on the services	» What were the perceived outcomes and impacts of services by patients and family caregivers? » Did patients and family caregivers think that the services had achieved its goals?	In-depth interviews with patients and caregivers conducted by HKU researchers Systematic sampling

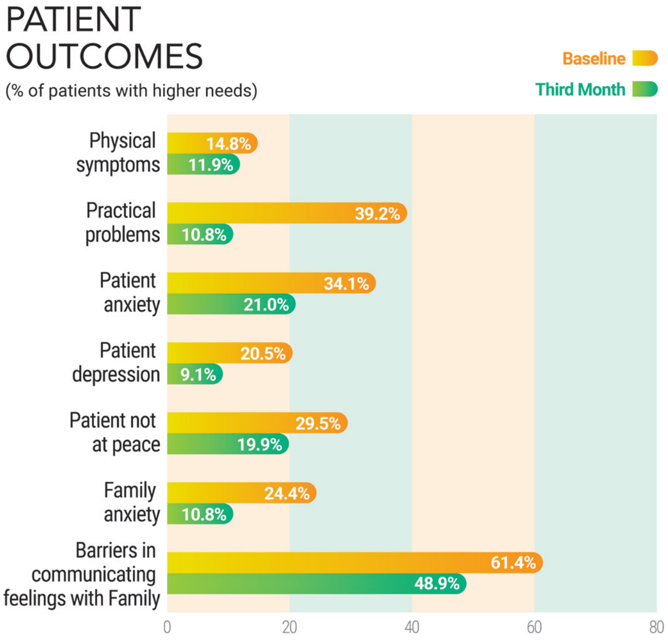
PRELIMINARY FINDINGS

Between 1 January 2016 and 31 March 2018, among 517 patients and 477 caregivers who received the services, 176 (34%) patients completed all assessments, 105 caregivers (22%) completed the first two assessments and 107 caregivers completed the post-death T2 assessment. The main reasons for attrition of patients were death (39.4%) and clinical deterioration (21.7%), whereas refusal (45.2%) and failure to arrange an interview time (25.3%) were the primary reasons for attrition of family caregivers. There were no significant differences in demographics of patients with or without assessments. Patients received an average of 6.6 months of service (standard deviation (SD)=6.5). They had a mean age of 76.4 years (SD=10.9) and there were no gender differences. There was a range of major diagnoses, including cancer (40%), chronic obstructive pulmonary disease (21%), end-stage renal disease (19%), Parkinson's disease (6%), motor neuron disease (5%) and heart disease (4%). Family caregivers were mainly female (77.1%), middle-aged (mean=58.8 years, SD=13.0), and reflected similar percentages of spouses (44.8%) or adult children (45.7%) of patients. They had high involvement in caregiving and provided, on average, 59.3 hours of care per week (SD=60.3) to patients. Over half of these family caregivers were also suffering from one or more chronic diseases.

To stratify patients into groups of high and low needs, a threshold level was set for each outcome indicator at mean baseline score plus one standard deviation. A score above the threshold level represented high needs. Distributions of high and low needs at baseline (T0) and at the third month were compared. At baseline, the majority (85.2%) of participants reported low needs in physical symptoms. This might be attributable to the hospital-based PC received by over half of these patients at the time of programme admission. Patients indicated that their greatest problems were with sharing feelings and practical concerns, with the highest reported proportion of high needs when compared to other psycho-spiritual distresses. As anticipated, patients encountered practical difficulties related to residing in the community.

Regarding psychological distress, studies have reported that Chinese patients tended to report less psychological distress than their Western counterparts (Sham, Chan, Tse & Lo, 2006). Some have explained this finding as the tendency of Chinese people to translate psychological distress into somatic presentations (Zhou et al., 2011), while others have suggested that cultural beliefs of accepting fate help elderly Chinese patients face death anxieties (Lo, 2006). From our observations, a large number of older Chinese patients found it difficult to articulate their inner feelings, which might have impeded their capacity to share feelings not only with family members, but also with the assessors. Lower proportions of caregivers at baseline reported high needs when compared to patients, with around 15% reporting high caregiver strain and 17% reporting low intimacy in relationships with patients.

After three months of service, reduced percentages of the high-need population were observed in all assessed areas for patients and caregivers (see **Figures 5.2** and **5.3**). The most obvious improvements were in practical issues, family anxiety and barriers in communicating feelings. Paired t-tests comparing baseline and three-month data found that all changes in the third month were statistically significant. The prevalence of complicated grief was 9.3% among the assessed bereaved caregivers, which was lower than the reported prevalence of 13.9% elsewhere (Li & Prigerson, 2016). Patients and caregivers' monthly utilisation of medical service remained low throughout the evaluation period (see **Figures 5.4** and **5.5**).



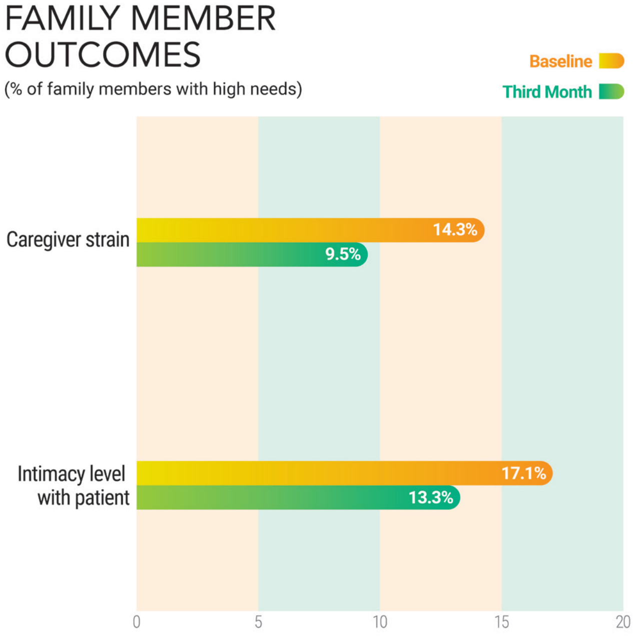
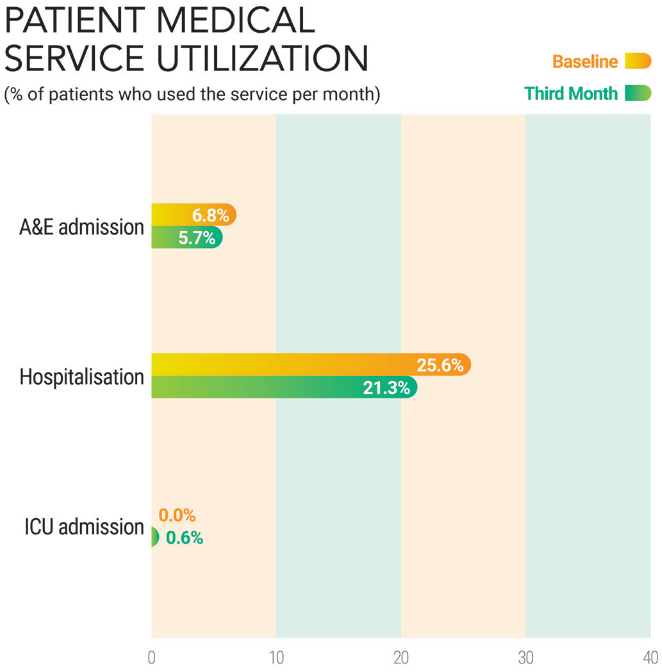


Figure 5.2 Changes in Patients' Outcomes after Three Months

Figure 5.3 Changes in Family Members' Outcomes after Three Months



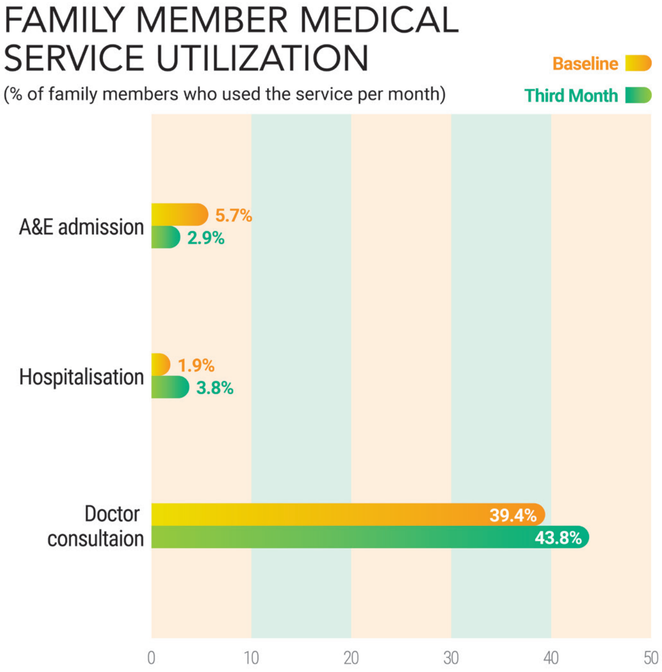


Figure 5.4 Impacts on Patients' Medical Service Utilisation after Three Months

Figure 5.5 Impacts on Family Members' Medical Service Utilisation after Three Months

The satisfaction survey was completed by 73 patients and 65 family caregivers, whil e in-depth interviews were arranged with nine patients and nine caregivers. Overall, patients and family caregivers were very satisfied with the service, with overall mean satisfaction scores of 9.1 (SD=1.1) and 8.8 (SD=1.2), respectively (out of a possible score of 10). High ratings (means greater than 8.5) were obtained on most service components, comprising psychosocial support, communication, care planning, information and caregiving stress relief. The only element that did not rate highly was satisfaction with symptom relief. These results mirror the stronger emphasis on psychosocial care of the service models. Both patients and caregivers reported highest satisfaction with the service in engendering dignity and respect for patients and caregivers.

Support relating to the six intervention foci of holistic care were reported by interviewees. The importance of information and practical support was identified in all cases, with psychosocial care being the second most frequently mentioned support. Respondents found practical support pivotal to their QoL, e.g. equipment loan, being escorted to appointments, receiving caregiving advice and assistance with navigation to community resources. These services greatly relieved their anxiety about returning home upon hospital discharge, as well as during the times when the patient's condition changed. Regarding psychosocial care, the activities that were highly appreciated by respondents included creation of life-review books, family reconciliation, wish fulfilment, surprise activities on special dates, engagement in hobbies, family outings and facilitation of saying goodbye when the final days arrived. A patient reported that he forgot his pain when engaged in leisure activities. This showed how psychosocial interventions perhaps helped him with symptom relief. For some family members, these interventions helped restore a normal family life and ameliorate patient and caregiver anxiety and loneliness through distraction and introduction of quality family times. Most interviewed bereaved family members reported no remorse, acknowledging that they had been helped in providing the best they could for the patient, in collaboration with the service team.

Notably, the people who were interviewed presented diverse experiences and needs at the patient's EoL. These were determined by the diagnosis, illness trajectory, variations in patient and caregiver's characteristics, and family resources. Interventions were essentially needs-based, and were adjusted in a timely and flexible manner in response to the changing needs of patients and caregivers, across illness trajectories. A few family members mentioned that timely support at critical times (such as hospital discharge, sudden deterioration of the patient's condition, point of death, as well as immediately after death) were most helpful to them. Regarding improvements in the services, patients usually wished for more support to alleviate the caregiver's burden, whereas caregivers mentioned nursing care support, respite services, sitting (or visiting) services and financial support.

The data collected over the last two years has provided valuable information and clear directions towards optimising effectiveness by model integration, and further improving the evaluation design. These are discussed in the next section.

LEARNINGS, REFLECTIONS AND WAY FORWARD

GENERATING EVIDENCE ON THE EFFECTIVENESS OF THE JCECC COMMUNITY-BASED EoLC MODELS WITH A COMPREHENSIVE OUTCOME EVALUATION FRAMEWORK

Our experience has shown that the evaluation framework successfully captures the intended outcomes for patients and caregivers. The framework encompasses practical, physical, psychosocial and caregiving aspects. The selected outcome indicators are responsive to the effect of interventions after three months of delivery. The satisfaction surveys identified that patients' and family caregivers' perceived outcomes were highly positive, and these mirrored the intervention foci. Moreover, data collected through in-depth interviews provided important and additional information to the quantitative outcomes. This data provided insights into effective components in the complex care models, and it shed light on the mechanisms by which these interventions worked. For example, timely and needs-based specialised EoL psychosocial care for patients and caregivers and also practical and caregiving support for caregivers were found to relieve distress of both patients and caregivers, restore normal life activities to families and ensure maintenance of dignity, which eventually contributed to patient QoL. The evaluation framework has generated preliminary evidence that supports the effectiveness of the JCECC community-based EoLC models. By synthesising the findings of the mixed-methods studies, the effective components in the different models have been identified. This had helped to build future care models that are unified in purpose and that have integrated components.

CAPTURING WHAT MATTERS TO CHINESE PATIENTS

The core outcome measure IPOS was developed for patients in Western countries. Despite the promising results in the JCECC evaluations, cultural adaptation and validation are needed to affirm the relevance of this instrument in Chinese contexts. For instance, the responses to the open-ended question in IPOS revealed prevailing concerns related to dignity and autonomy among patients did not include a scale. Cognitive interviews with patients and caregivers on the appropriateness of Chinese-translated IPOS will help ensure the measurement captures what matters most to Chinese patients at EoL. The validation study is currently underway in a collaboration between the HKU research team and researchers at King's College London.

COMPLETING THE EVALUATION FRAMEWORK WITH EVALUATIONS BEYOND OUTCOMES

Process and economic evaluations should be included in future evaluations of the JCECC Project programmes. Process evaluation of complex interventions has been increasingly emphasised in the last decade in line with guidance by the UK Medical Research Council (Moore et al., 2015). Process evaluations ask questions such as 'Was the designed intervention delivered as planned?', 'What is the mechanism leading to changes?' and 'Will an intervention work the same in other contexts?'

Answers to such questions are crucial to optimise the intervention, and then replicate and generalise it (Medical Research Council, 2006). To answer these questions, the first step would be to assess the implementation objectively. Service records in Study 1 can be analysed in relation to outcomes and impacts. Moreover, purposive sampling according to patients' and caregivers' characteristics can be used in the in-depth interviews in Study 4 to explore how contextual factors might influence service delivery and effectiveness. Economic evaluations of the service models are essential to inform policymakers in resource allocation. A commonly used cost-utility analysis is the notion of the Quality-Adjusted Life Year (QALY), which takes both the length and quality of life into consideration, and reports the cost per unit outcome gained. On the other hand, calculating Social Return on Investment (SRoI) is a methodology for cost-benefit analysis, which has been applied to evaluate the impacts of a preventive care programme "Ageing-in-Place", a scheme implemented by the Hong Kong Housing Society (Hong Kong Housing Society, 2016). The principles, strengths and limitations of various economic evaluation methods have been discussed elsewhere (Dixon, 2018; Hodgson, 2012; Rudmik & Drummond, 2013). Appropriate economic evaluation will be incorporated into the current JCECC evaluation framework after considering the feasibility of collecting the requisite data, and the compatibility of economic evaluation methodologies with the existing evaluation study designs.

SUMMARY

Our experience has shown that a common evaluation framework underpinned by a mixed-methods research design is feasible, able to capture multidimensional outcomes of complex interventions in the four models being tested and can identify effective important intervention components for a future integrated model. The preliminary evaluation findings support the effectiveness of the four care models in improving QoL of patients and family caregivers. To further advance the current evaluation framework, process and economic evaluations should be included. Apart from evaluation, the clinical meaningfulness of outcome indicators, and their ability to inform clinical practice are as important as the evaluation design. We have set pilot threshold levels in the outcome indicators to differentiate high and low needs. These threshold levels can be applied to a risk-stratifying assessment tool to facilitate screening and to inform interventions. It is vital to articulate screening, intervention components and outcomes in any future integrated model in order to promote evidence-based practice that delivers targeted and informed interventions. It is anticipated that by sharing experiences in the development, pilot-testing and subsequent refinement of the evaluation framework, the findings will translate to learnings that will benefit similar future initiatives.

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